

Survivorship: A Psychosocial Perspective

A conversation with Brad Zebrack, PhD

Brad Zebrack, PhD, is assistant professor at the University of Southern California School of Social Work. His teaching and research interests are in the area of health, medicine, and quality of life, with a particular focus on the impact of cancer on patients, survivors, and their families. A long-term survivor of Hodgkin's disease, Dr. Zebrack currently serves on the board of directors for the American Psychosocial Oncology Society and the Association of Oncology Social Work, for which he chairs the Social Workers in Oncology Research Group.

Q. *A surgical oncologist and cancer survivor, Dr. Richard Reiling chose survivorship as the theme of his ACCC Presidency (April 2007–April 2008). What are the key issues in cancer survivorship today from the provider and patient perspective?*

A. From a medical point of view, I think providers need to be prepared to deal with some of the ongoing or long-term effects of cancer. Many people are living longer with cancer, but they are struggling with physical, psychological, or social late effects of the cancer or cancer treatment that can extend many years beyond the end of their treatment. So the focus on survivorship has been for the medical establishment to start paying attention to some of these associated effects.

From the patient's point of view—survivorship is a very unique and individualized experience. There is no one way or one model way of being a cancer survivor. While from the medical point of view we want to provide comprehensive programs and services, from the patients' point of view, they may not always want to take advantage of these services. Simply knowing that these services are available may be helpful.

Q. *What would you suggest are the first components that community cancer centers should attempt to address in their survivorship programs?*

A. The first goal that comes to mind is taking care of any long-term physical symptoms or physical side effects associated with cancer and its treatment. So many of the other aspects of cancer survivorship—psychological well-being, social well-being, quality of life—are so often tied back to physical symptoms. People who have fewer physical symptoms—they don't have pain, they don't have discomfort—are just much better off in many other aspects of their lives.

Then I think the other critical component for a survivorship program is the psychosocial component. Community cancer centers should have trained professionals who can check in and touch base with cancer survivors and assess their functioning in other aspects of their lives.

For example, employment is a critical component.



People take such a financial punch in the stomach as the result of going through cancer treatment today. In fact, 50 percent of bankruptcies in the United States are somehow associated with medical care and people being swallowed up by the cost of medical care. So many other aspects of people's lives are affected by this one issue: the financial impact of cancer.

The focus of a comprehensive cancer survivorship program goes beyond treating the physical late effects. In other words, when a cancer survivor has his or her symptoms addressed but then walks out of the clinic and feels like he or she does not have help dealing with financial issues, it is a missed opportunity. Instead, a social worker or a mental health professional can help identify these long-term problems or issues and then offer assistance.

Q. *What has your research taught you about the needs of cancer survivors?*

A. One size does not fit all. Take support groups, for example. Support groups are valuable for a certain group of people. And I think we still need to do more research into identifying the people who are most likely to benefit from support groups.

The growth of the Internet and the ability of people to go online at 3:00 am and find information or check into a bulletin board, forum, or chat room have opened up a whole new set of support for cancer survivors. People who are more private and not entirely comfortable going to a support group can use these new forms of technology to

access emotional support in the privacy of their own home. So to answer your question, there is no set survivorship “standard.” We have to still try to figure out what’s going to work for which groups of people.

Q. *Can you describe the Impact of Cancer Scale Tool that you’ve developed, which is aimed at assessing the effects of cancer on different aspects of survivors’ lives?*

A. Prior to the development of this scale, there were very few instruments that were measuring the quality of life of cancer survivors. Some of the emerging quality of life scales were attempting to assess areas such as physical, psychological, and social well-being; impacts on spirituality; how cancer affects an individual’s sense of purpose in life, etc. We felt that when you look at these impacts on different people’s lives, it’s hard to tease out how much of those impacts are really related to cancer and how much of those are just naturally occurring changes in life. It was one obstacle we wanted to overcome.

When we look at much of the qualitative research in cancer and listen to and read people’s stories, most cancer survivors talk about how their life has changed after cancer. The other commonality in many stories and narrative is that cancer survivors often talk about how there is an interdependence in the physical, psychological, and social aspects of their lives. In fact, they don’t exist as independent domains. The physical affects the psychological well-being; psychological well-being can affect the extent to which someone feels comfortable interacting out in the social world. If you’re depressed, you don’t want to get up and go to work. And if you don’t have work, it’s going to make you depressed. There’s a two-way arrow that connects these domains. So we wanted to create an instrument that captured that interdependence. The *Impact of Cancer Scale Tool* has 82 items that cover 10 different domains of people’s lives that seem to be affected by cancer.

Q. *And how can a community cancer program use this tool?*

A. Community cancer centers can give this to cancer survivors and score them in each of the 10 different subscales. There are five positive impacts subscales and five negative impact subscales. So providers can get a picture of the extent to which their patients are saying they have more positive and/or more negative impacts of cancer. One of the interesting results is that it’s not necessarily one or the other. Some people report both high positive changes as well as high negative changes.

Q. *How do you see community-based cancer programs using the information they gathered from this tool?*

A. The information could be used to engage cancer survivors in further discussion about the specific problems they might be having in their life. So for patients who have a really negative perception of the way cancer has affected their life, a social worker or psychologist or mental health professional can then use that information as a starting point to engage a person and say, “Let’s talk about different ways that cancer has affected you.”

For example, one of the subscales is called Life Goals. You could look at someone’s score on this section and get a sense that this person really has no sense of a future; that they really don’t have any sort of guiding light or sense of an overall goal or, if they have goals, they

don’t feel like they can achieve those goals. As a social worker I might then sit down with this person and say let’s talk about this issue: *Why do you feel this way? What do you think are the barriers that are preventing you from either establishing goals for your future or achieving the goals that you have?*

Our scale can help identify and maybe even prevent negative problems that cancer survivor’s might be dealing with, but it also helps to bolster and promote the positives. (The *Impact of Cancer Scale Tool* is available on ACCC’s website at www.accc-cancer.org.)

Q. *Would you describe your current research interests?*

A. My research now is looking primarily at older adolescents and young adults and the impact of cancer in that particular age group. There are data out there to suggest that young people between the ages of 15 and 40 have not experienced some of the improvements in mortality and long-term survival that both pediatric and older adult patients have experienced. Why has this age group not experienced some of the same improvements? There is both theory and data to suggest that it might be the biology of their cancer. It might be the way that physiologically they respond to therapy that’s different from a child and different from an older adult. It might be linked to the time of life. So there is a lot of supposition about what it is about these young adults that their outcomes are disparate.

I have funding right now to do a longitudinal study of young adults, first approaching them within the first few months of treatment and assessing the physical, psychological, and social impacts of their diagnosis and then following them over a period of two years. We hope to be able to tease out useful data from this study because—as I mentioned earlier—one of the struggles is how do you separate the effects that someone is experiencing as related to cancer as compared to what might have happened in their lives normally anyway? By being able to follow young adults longitudinally, we can pay close attention to the changes in their lives that they are attributing to cancer or cancer treatment.

Q. *Can you suggest any good sources of information for community cancer centers and share any final thoughts?*

A. There are some good model survivorship programs, for example, the post-treatment resource center at Memorial Sloan-Kettering Cancer Center. Particularly for young adults, I think a lot of the model programs are Internet based, and I would suggest a website called Planet Cancer as a model for promoting peer support and peer relationships for young adults.

Julia Rowland, PhD, a developmental psychologist who is now director of the Office of Cancer Survivorship at the National Cancer Institute, suggests that in cancer there are universal effects that happen to everybody, and yet, when you then look at it from a developmental perspective, depending on the time in life in which a person is diagnosed, they *experience* those universal impacts differently. A 50 year old diagnosed with colon cancer will have different concerns than a 25 year old diagnosed with Hodgkin’s disease. I would suggest that community cancer centers looking to grow a cancer survivorship program should step back and think about cancer across the lifespan.